

Women living with endometriosis unite to make their voices heard

Submitted by ncd-admin on 9 May, 2018 - 23:16



Language English



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We are at a time of change for millions of women with endometriosis everywhere - built upon their own strength and dedication. Julie Prilling, the designer and data scientist who created the EndoStats platform, shares her insight on the urgent need to raise awareness of the illness and generate meaningful action.

Many diverse people, one voice for action

Most people advocate for illness cures and funding. The endometriosis community's efforts extend beyond this to just wanting society to know the illness exists. That we exist. And we are many. Advocacy today involves diversity in cultures, people and groups that evolve messages together and accelerate a one voice for action. For decades, advocates have been working to educate the need for better healthcare. Now united with the youth of the next generation and the connectivity of global social media, we are here to say: we will not stop until we see change. We, as women and girls, deserve better. We will march, petition, and knock on doors of media and policy until we are heard.

The endometriosis community has united to use the collaborative patient voice to initiate systemic change. Connecting with each other through listening and sharing has driven the endo civil society to find ways within the system to unite our voices as a group on initiatives for progress. Every day advocates are waking up and impacting change through writing books, developing apps and documenting our lives through film. We are changing the narrative by collecting our own data and simplifying the research to show the true depth of the illness. The endometriosis movement is taking this storytelling and bringing awareness to effect policy change and updates to our standards of care. No, we aren't doctors, we are experts in our own bodies.

Only 20% of the general public have heard of endometriosis

Raising awareness that an illness exists requires effort beyond strength and dedication. We want our doctors, teachers, employers, friends and family to know endometriosis exists. We exist - living with this, and need to be supported by our communities.

Endometriosis is a complex illness that is found throughout the entire body. Symptoms can range from cycle pain to lung collapses. For most of a woman's life, this limits her ability to be involved with school, work, friends and family - on an average of 11 hours a week. Currently there is no cure. 1 in 10 women have been diagnosed with endometriosis, which is 176 million, but there are millions living undiagnosed. While there is an average of a 7-10 year delay in diagnosis, this number can be as high as 20-30 years, since there is no diagnostic test and only limited imaging for endometriosis. Exploratory surgery is currently the only option to clarify diagnosis, and sometimes multiple surgeries are required to treat.

We aim to change this. All women's health is in urgent need of updating

The movement is now. Patients shouldn't know more about endometriosis, or any other illness, than their doctors. We shouldn't have to teach our medical providers in order for us to receive effective treatment. There is a lot of misinformation and practicing methods that are in need of an update. Most doctors respond to pain as just a normal part of womanhood. Pain is not normal. NHS states endometriosis is one of the most excruciating pains humans can experience, aligning to the pain of a heart attack.

Imagine going to the hospital with a heart attack and having to explain to the doctors what it is and that it exists. Imagine going through this every month. Now imagine you're 12 or as young as 8 years old. Watching our youth not only struggle with this but stand up for their reproductive rights inspires all of us to make sure that future generations have better standards of care for women's health.

We know patient-driven change is the key, and want to collaborate with physicians and policy makers to impact the progress. Change is already upon us. With patient advocacy, in the past year Australia has initiated the first national policy on endometriosis and the NCD Alliance brought us into the conversation with UN policy. The World Health Organization has shined a light to our stories, and are updating the definition of endometriosis which includes thoracic into the ICD-11 codes. The EndoMarch started five years ago to bring societal awareness and is now in 56 countries lighting up the world in yellow from Niagara Falls to Ghana.

Fortunately, we are at a time of technology, collaboration and motivation

Like the Sustainable Development Goal project, a top down, one-source platform is key to achieving our global health goals. Designing and communicating education with united missions for healthcare can be made simple. This can be created to be interactive and motivating to take part in progress; whether it be personal, or through education and policy.

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Published on NCD Alliance (<https://ncdalliance.org>)

As a designer and data analyst, I created EndoStats three years ago because doctors weren't listening to me. It indicated a need for research to be simplified and the creation of universal education tools. I thought I was rare having Thoracic Endometriosis until I listened to many others online that had the same symptoms. I created the platform to simplify the research, accelerate patient statistics and unite our voices for change. These infographics are being translated by global advocates around the world.

As patients and advocates, part of our task is sharing the correct information with society, media and our doctors. The [EndoWhat film](#) [1] is a great source for endometriosis information for all ages. This is an example of "clear communication" of healthcare information that is a result of uniting doctor, patient and societal perspectives. It also displays the commercial impacts, like sugar, along with the environmental detriments that impact the illness.

As with lot of NCDs, there are measures to take

- There is a \$2 billion market in the US for treatments that just control the pain from endometriosis, yet there is limited funding and research for diagnostic test, imaging and education. The social impact of our health should out-weigh profit.
- Endometriosis is an inflammatory illness which requires an anti-inflammatory diet. Current research is being focused on the microbiome, our diet and all chronic illnesses. These are driving factors into preventative care and are in need of research and funding.
- More research is needed into how chemicals in the environment affect NCDs. NYU Langone Medical Center's data shows that the health effects from endocrine disrupting chemicals cost the US \$340 billion. The cost of endometriosis and fibroids is \$43 billion.

In order to move forward to improve lives, there needs to be an open dialogue among patients, physicians, researchers and policy makers that is evidence-based. Together, with patients' voices, platforms engaged in citizen science can be created that are motivating and also beneficial to everyone involved.

About the author

Julie Prilling ([website](#) [2], [@EndoStats](#) [3]) has worked as a consultant on projects that work on systemic progress for 15 years doing strategy, research and design. She has had endometriosis since age 12. Along with using her skills to bring change through simple messaging, advocacy for change is a part of her life. Her aim is making sure that future generations will have better health care during their lives. Julie created and curates the platform, [EndoStats](#) [4].

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[1] <https://endowhat.com/>

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[3] <http://twitter.com/EndoStats>

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